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Capturing the patients' perspective: patient-reported outcomes for subarachnoid hemorrhage

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Clinical outcomes such as survival and recurrence, and clinician-reported outcomes including measures of patient function like the Barthel Index, have an important role in assessing effects of treatment and disease at both individual and population level. However, they do not capture patients' perspective of the consequences of disease on functional status, well-being, health-related quality of life, or symptom burden.(1) Patient Reported Outcome Measures (PROMs) questionnaires, completed by patients, provide a quantitative measure of patients' own experience of their health, including burden of disease and effects of treatments or interventions.(1) Broadly, PROMs are categorised as generic (such as the Short-Form-36) or condition-specific (such as the Stroke-Specific Quality of Life Scale) (Table 1). Ideally, patients should participate in all stages of PROM development – both as research partners and participants to ensure relevance and acceptability.(2) However, many PROMs are developed without patient input.(3) In this issue of NEUROLOGY, Saigle et al. report a scoping review of patient, family, and carer input into the development of PROMs for subarachnoid hemorrhage (SAH).(4) They include studies that incorporate patient, family, and carer perspectives on priorities for SAH-specific PROM content, co-development, and evaluation.

The authors identified 12 (distinct) relevant articles that included 879 patients with SAH and 241 carers. The systematic and comprehensive search strategy alongside robust methodology, including independent screening by two reviewers, represent key strengths of the review. The failure to include relevant grey (non-academic) literature, such as the priority setting haemorrhagic stroke workshop completed by the Stroke Association (UK charity) in 2014, constitutes a limitation of their approach.(5)

The majority of studies identified by the review described symptoms or outcomes 'spontaneously' reported by participants. However, none of the studies attempted to establish those most important to participants. Only two PROMs involved SAH patients or their carers in the development: the

Wessex Patient Carer Questionnaire (WPCQ) and the Subarachnoid Hemorrhage Outcome Tool (SAHOT). In addition, one study evaluated the relevance of a pre-existing PROM, the Functional Status Examination (FSE) to SAH survivors. None of these PROMs included patient/ carer involvement at all stages of PROM development and evaluation, and most underreported or provided non-specific details about patient/carer involvement.

This review focuses specifically on SAH survivors and carers – stakeholders frequently excluded from stroke outcomes research.(6) It highlights the lack of knowledge regarding those symptoms and outcomes that are most important to these patients and their carers. The recently developed International Standard Set of PROMs after stroke explicitly excluded SAH due to differences in treatment and outcomes.(6) Furthermore, PROMs have had limited use to date in SAH randomised controlled trials. A systematic review found patient-reported quality of life measures reported in only 8.5% (11/129) of studies and all were generic PROMs.(7) The review by Saigle *et al* highlights the need for greater involvement of patients and carers in the development and evaluation of SAH PROMs, and the importance of wider implementation of PROMs in SAH research and clinical care.

PROMs provide a method to capture patients' perspectives and can be integrated into clinical care to support communication between patients and clinicians, facilitate shared decision making, and monitor adverse events.(1) At an aggregate level, PROMs have potential to inform service delivery and commissioning.(1) However, they require comprehensive patient involvement in design and evaluation to ensure they represent factors patients believe important, and to increase the likelihood patients will complete them. The increased drive for patient-centred healthcare, shared-decision making, and involvement of patients in co-production of research should extend to SAH. SAH research capturing relevant and patient focused outcome measures will help achieve this goal.

The hundreds of different generic and condition-specific PROMs available create difficulties for clinicians deciding which PROM(s) to select for clinical practice. In consultation with key stakeholders, including patients, families, researchers, clinicians, allied health workers and policy-makers, the COMET (Core Outcome Measures in Effectiveness Trials) Initiative is developing a Core Outcomes Set for SAH clinical research (2016-2020).(8) This Core Outcomes Set will provide a valuable resource in the future to provide recommendations for standardised outcomes (clinical, clinician-reported and patient-reported) for this population. However, it will not recommend which instrument to use to measure the outcomes. Clinicians should consult their patient groups to inform decisions regarding the appropriate and meaningful PROM(s). The WPCQ and the SAHOT have been developed with input from SAH patients and carers, so may be more acceptable and relevant than other stroke-specific or generic PROMs. Other considerations include: psychometric properties, rationale for PROM collection, interpretability, resources, and cost.

Successful implementation of PROMs into clinical practice and research requires meaningful and easy to interpret PROM data. This requires a 'bottom-up' approach whereby patients, carers, clinicians, and other key stakeholders actively participate in development, selection, and implementation of PROMs. Developers should report this involvement transparently to enable quality appraisal and learning for other disciplines. The Saigle *et al* review provides a useful summary of the current involvement of patients in SAH PROMs, but highlights the lack of patient involvement in PROM development to date. By doing so, they identify an important area for future SAH research.

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Table 1: Comparison between generic and condition-specific PROMs.

Type of PROM	Strengths and Limitations	Example PROM	
Generic: Designed to be used in any patient population	**Strengths:** -Enable comparison across different health problems or populations. -Useful when there are no condition-specific PROMs available. -Useful for patients with multi-morbidities. **Limitations:** -May not provide an adequate level of detail. -Can be less sensitive to capturing change.	**Name:**	Short Form-36 (SF-36)
		Domains:	N=8 Physical functioning; Role limitations-physical; Role limitations-emotional; Bodily pain; General health; Vitality; Social functioning; Mental health
		Questions:	N=36
		Example question:	*In general, would you say your health is:* *a) Excellent* *b) Very Good* *c) Good* *d) Fair* *e) Poor*
Condition-specific: Developed for a particular disease, condition or injury	**Strengths:** -Specifically measure problems or aspects of health relevant to the condition. -Can be more responsive to change. **Limitations**: -Unable to make comparisons with the general population or other conditions.	**Name:**	Stroke-Specific Quality of Life Scale (SS-QOL)
		Domains:	N=12 Energy; Family roles; Language; Mobility; Mood; Personality; Self care; Social roles; Thinking; Upper extremity function; Vison; Work/ productivity
		Questions:	N=49
		Example question:	*It was hard for me to concentrate:* *1) Strongly agree* *2) Moderately agree* *3) Neither agree or disagree* *4) Moderately disagree* *5) Strongly disagree*